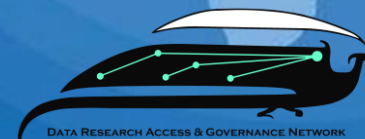


# Governance of confidential research data in low- and middle-income countries

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# Background

- 2021 – The present and future of confidential microdata access
- Summer school
- Gap in research (as far as we know)

# Unresolved questions

- What are the attitudes towards data sharing in LMICs?
- What are the challenges in using confidential data in LMICs?
- What is used as a guide for the governance of confidential data in LMICs?
- What happened in LMICs during the COVID-19 pandemic?
- How can we develop support networks?

# The workshop

- Some 40 attendees. Mainly from Africa, Latin America, and West and South Asia .
- Pre-workshop survey
- Three sessions over a week
  - Discussion on attitudes, main challenges and what happened during COVID.
  - Discussion of what is working well and what isn't.
  - Ways forward for data governance in LMICs.

# Establishing the current state of play

- Technology
- Organisations
- Societal context

# Establishing the current state of play Technology

- Data availability and quality is a challenge
- Low bandwidth is common
- Paper-based data collection and physical storage.
- Research data centres/data enclaves are rare
- Remote access to data has increased, but there are issues.
- Most researchers are unfamiliar with SDC and PETs.

# Establishing the current state of play

## Organisation

- Guidelines and training are needed.
- Training designed in HICs is sometimes less adequate in LMICs.
- Approval processes are commonly designed in HICs.
- Low funding and short-termism limits long-term capacity building.
- LMIC data is sometimes managed in HICs.

# Establishing the current state of play

## Societal context

- Data sharing competes with other priorities.
- Limited communication and collaboration between agencies.
- Low trust between (and within) organisations.
- Governments and key institutions are often unaware of importance of data access.
- Governments are less involved in data governance policy.
- Less public awareness and engagement limits support for initiatives.



# Ways forward

- Training and information resources
- Accreditation and auditing
- Changes in attitudes
- Knowledge exchange networks

# Training and information resources

- Accessible guidance across the range of data governance activities, including templates for best practice.
- High-level principles-based guidelines on data governance
- LMIC input for workshops developing good data governance principles – ensuring guidelines are relevant
- Specific case studies and examples reflecting the likely needs of LMIC users
- Support for hierarchical training models including training for champions and train-the-trainer materials.

# Accreditation and auditing

- Models of accreditation that can be adapted and adopted
- Accreditation provides a link between principles-based planning and implementation.
- Potentially based around the Five Safes.
- Should have validity outside of local contexts.

# Knowledge exchange networks

- Almost no experts in policy design in LMICs.
- LMICs should be included in existing networks
- LMIC specific networks should be developed
- Regional, national and sectoral champions have a key role here
- Engagement with non-obvious events can also help.

# Changes in attitudes

- Data owners' attitudes
- Data users' attitudes
- Government institutions' attitudes
- Funding agencies' attitudes
- Public attitudes and engagement

# Who can do what?

- International agencies and NGOs
- NSIs, local research institutions and public health bodies in LMICs
- National and regional champions
- IRBs and other actors
- Professional practice and research associations
- Academia

# Let's stay in connected

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